REVISTA DE ENFERMAGEM REFERÊNCIA
homepage: https://rr.esenfc.pt/rr/
ISSNe: 2182.2883

RESEARCH ARTICLE (ORIGINAL)

The profile of technology-dependent children and adolescents in a pediatric intensive care unit

Perfil de crianças e adolescentes dependentes de tecnologias em saúde numa unidade de terapia intensiva pediátrica

Perfil de los niños y adolescentes dependientes de tecnologías sanitarias en una unidad de cuidados intensivos pediátricos

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Received: 08.03.22
Approved: 14.12.22

Abstract
Background: Technology-dependent children and adolescents are recurrently admitted to intensive care units. These admissions prompt the need for follow-up care to maintain these children's and adolescents' health.
Objective: To identify the demographic and clinical profile of technology-dependent children and adolescents at the time of hospital discharge from a Pediatric Intensive Care Unit (PICU).
Methodology: This is a quantitative, documentary, and retrospective study based on medical records of technology-dependent children/adolescents admitted to the PICU of a teaching hospital in southern Brazil.
Results: The study observed a predominance of white male children up to one year of age coming from the pediatric emergency room, with a history of conditions originating from the perinatal period, the use of long-term medication, and the prevalence of diseases of the respiratory system and congenital malformations.
Conclusion: This group represents a challenge for healthcare services. In addition to the current diagnosis, past complications can affect the prognosis. Implementing care action plans that consider the needs of children/adolescents and their families is recommended to ensure comprehensive care.

Keywords: child; adolescent; intensive care units; pediatric; chronic disease

Resumo
Enquadramento: As crianças e adolescentes dependentes de tecnologias em saúde experienciam recorrentes internamentos em unidade de terapia intensiva, o que desencadeia necessidades de acompanhamento para a manutenção da sua saúde.
Objetivo: Identificar o perfil demográfico e clínico de crianças e adolescentes dependentes de tecnologias em saúde no momento da alta hospitalar de uma unidade de terapia intensiva pediátrica.
Metodologia: Estudo quantitativo, documental e retrospetivo, desenvolvido a partir de prontuários de crianças/adolescentes dependentes de tecnologia em saúde internados em terapia intensiva pediátrica num hospital escola do sul do Brasil.
Resultados: Predominância de crianças de até um ano de idade, de etnia branca, do sexo masculino, provenientes do pronto-socorro pediátrico. História pregressa de afeções originadas no período perinatal, utilização de medicação contínua. Predomínio de doenças do aparelho respiratório e malformações congénitas.
Conclusão: Este grupo constitui-se num desafio para a assistência em saúde. Além do diagnóstico atual, complicações pregressas podem interferir no prognóstico. Sugere-se planear as ações de cuidado, considerando as necessidades das crianças/adolescentes e suas famílias em prol da integralidade do cuidado.

Palavras-chave: criança; adolescente; unidade de terapia intensiva pediátrica; doença crónica

Resumen
Marco contextual: Los niños y adolescentes dependientes de tecnologías sanitarias sufren ingresos recurrentes en unidades de cuidados intensivos, lo que dispara las demandas de seguimiento para mantener su salud.
Objetivo: Identificar el perfil demográfico y clínico de los niños y adolescentes dependientes de tecnologías sanitarias en el momento del alta hospitalaria de una unidad de cuidados intensivos pediátricos.
Metodología: Estudio cuantitativo, documental y retrospectivo, desarrollado a partir de historias clínicas de niños/adolescentes dependientes de tecnologías sanitarias ingresados en cuidados intensivos pediátricos en un hospital universitario del sur de Brasil.
Resultados: Predominio de niños de hasta un año de edad, de etnia blanca, de sexo masculino, procedentes de las urgencias pediátricas. Antecedentes de trastornos originados en el período perinatal, uso de medicación continua. Predominio de enfermedades del aparato respiratorio y malformaciones congénitas.
Conclusión: Este grupo constituye un reto para la asistencia sanitaria. Además del diagnóstico actual, las complicaciones pasadas pueden interferir en el pronóstico. Se sugiere planificar las acciones de atención considerando las demandas de los niños/adolescentes y sus familias para brindar una atención integral.

Palabras clave: niño; adolescente; unidades de cuidado intensivo pediátrico; enfermedad crónica

How to cite this article: Paines, L. P., Ribeiro, A. C., Kegler, J. J., Monteiro, A. S., Sehnem, G. D., & Neves, E. T. (2023). The profile of technology-dependent children and adolescents hospitalized in a pediatric intensive care unit. *Revista de Enfermagem Referência*, *6*(2, Supl. 1), e22028. https://doi.org/10.12707/RVI22028

Introduction

The implementation and strengthening of public policies focused on child health and the promotion of a holistic perspective in care delivery have reduced the child mortality rate, with a significant decrease in all regions of Brazil between 2000 and 2010 (Rodrigues et al., 2018). In association with public policies, healthcare scientific and technological advances have increased the survival of clinically fragile children that require continuous and, sometimes, highly complex care. This group of children was initially identified in the United States of America (USA) as Children with Special Health Care Needs (CSHCN) (McPherson, 1998). The term was later translated in Brazil to *Crianças com Necessidades Especiais de Saúde* (CRIANES). It represents children and adolescents between 0 and 18 years (Silveira & Neves, 2019) who have or are more susceptible to developing a chronic health condition, whether physical, developmental, behavioral, or emotional. These children and adolescents greatly depend on healthcare services and need to use medical devices/technologies temporarily or permanently (Góes & Cabral, 2017).

In the USA, 15 to 20% of the population between 0 and 17 years old (Bethell et al., 2014) are CSHCN. In Brazil, the absence of official data denounces the lack of visibility of CSHCN in the public health context, which hinders the implementation of policies directed to this group's particularities.

The care demands of CSHCN can be classified into five categories: developmental; technological; medication; modified daily life activities; and mixed demands (Cabral & Moraes, 2015). This study aims to identify the demographic and clinical profile of technology-dependent children and adolescents at the time of hospital discharge from a Pediatric Intensive Care Unit (PICU).

Background

Among CSHCN, technology-dependent children need one or more medical devices/technologies, such as mechanical ventilation, gastrostomy or tracheostomy tubes , to maintain their lives (Dias et al., 2020). These children often depend on intensive care and require recurrent hospitalizations at PICUs.

The needs of this segment of the population pose a significant challenge for healthcare professionals, particularly nurses. These professionals, who provide daily care, must deal with the more extended hospital stays and frequent (re)hospitalizations of technology-dependent children and adolescents.

Although the hospitalizations at the PICU of these children and adolescents are frequent, the knowledge about the clinical characteristics and hospital discharge of this population segment is still incipient, emphasizing the need to know this reality to improve health professionals' training and the quality of care provided. The lack of follow-up by Primary Health Care services after hospital discharge contributes to a greater demand for and consequent (re)hospitalization in highly complex healthcare services such as PICUs. However, these services are often not entirely effective, worsening the clinical condition of these children and adolescents (Neves et al., 2019).

Research question

What is the demographic and clinical profile of technology-dependent children and adolescents at the time of discharge from a PICU?

Methodology

This is a documentary, retrospective, quantitative and descriptive study based on the database of the matrix project entitled "Characterization of the morbimortality of children and adolescents discharged from a pediatric intensive care unit."

The matrix project aims to analyze the morbimortality of children and adolescents discharged from a PICU in 1995, 1997, 2005, 2007, 2015, and 2017. The PICU in the studied hospital was inaugurated in 1995. Thus, this year was chosen as the first of the research. The following years were determined following a historical sequence organized in biennia. The objective was to examine the evolution of the morbidity and mortality of children and adolescents during the 22 years of the unit's existence.

The PICU is located in a medium-sized public hospital providing highly complex healthcare services entirely through the Brazilian Unified Health System. This hospital is a reference in the central-western macro-region of Rio Grande do Sul. The PICU, where this study is set, has six beds, one of which is for patients requiring isolation.

The medical records of all the technology-dependent children and adolescents in the matrix project were selected by intentional sampling. The Child and Adolescent Statute (Brazil, 1990) defines "children" as individuals up to 12 years of age and "adolescents" as those aged from 12 to 18. Those using medical devices/technologies, such as gastrostomy tubes, nasogastric tubes, urinary catheters, colostomy tubes, ileostomy pouches, tracheostomy tubes, mechanical ventilation, and indwelling catheters for life maintenance, are dependent on health (Lima et al., 2015). The medical records without a discharge or death summary were excluded, as well as those in which the admission was only for exam retrieval, those whose access was not granted after five requests, those not found in the medical archive, and those without records in the intended years.

Data was collected for the matrix project from July 2018 to May 2019 by a team of previously trained collectors using a previously tested instrument consisting of demographic and clinical variables. It is worth noting that the collectors also had a manual they could consult in case of doubts regarding the completion of the instrument. Data were entered in the Epi-info® program (version 7.2.3.0) using independent double entry. Inconsistencies found during typing were checked and corrected. Data analysis

was performed in the R statistical program (version 3.6.1) using absolute (N) and relative (%) frequencies.

For data analysis, some variables were grouped, such as age range, considering infancy up to 1 year old, early childhood from 1 to 6 years old, middle childhood from 6 to 11 or 12 years old, and later childhood (adolescence) from 12 to approximately 18 years old (Hockenberry et al., 2018). The variables of birthplace and origin were classified according to the cities of the health macro-regions of the state of Rio Grande do Sul – north, south, center-west, *missioneira*, metropolitan, and *vales*. The ICD-10 (International Classification of Diseases - Tenth Revision) was used to categorize the patient's medical history, including the diagnoses, signs, and symptoms.

The matrix project was developed according to Resolution 466/2012 of the Brazilian National Health Council. It was approved by the Research Ethics Committee of the Federal University of Santa Maria, under opinion number: 2.711.094, and the Certificate of Presentation of Ethical Appreciation: 89344518.1.0000.5346.

Results

Of the total number of children and adolescents admitted to the PICU, technology-dependent children and adolescents represented 8.1% ($N = 9$) in 1995, 4.8% ($N = 9$) in 1997, 4.4% ($N = 3$) in 2005, 6% ($N = 7$) in 2007, 14.9% in 2015 ($N = 26$), and 13.7% ($N = 24$) in 2017. Table 1 shows the demographic profile of these children and adolescents.

Table 1

Demographic profile of technology-dependent children and adolescents admitted to the PICU in 1995, 1997, 2005, 2007, 2015, and 2017.

Demographic Variables	Frequencies											
	1995		1997		2005		2007		2015		2017	
	N	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)
Sex												
Female	2	22.2	4	44.4	2	66.7	1	14.3	10	38.5	14	58.3
Male	7	77.8	5	55.6	1	33.3	6	85.7	16	61.5	10	41.7
Ethnicity/Skin color												
White	8	88.9	6	66.8	2	66.7	3	42.9	22	84.7	17	70.9
Black	0	00	0	00	0	00	0	00	3	11.5	5	20.8
Brown	0	00	0	00	0	00	1	14.2	0	00	5	8.3
Yellow	0	00	0	00	0	00	0	00	0	00	2	00
Indigenous	0	00	1	11.1	0	00	0	00	0	00	0	00
Not Identified	1	11.1	2	22.1	1	33.3	3	42.9	1	3.8	0	00
Age												
≤ 1 year	7	77.8	8	88.9	1	33.3	5	71.4	11	42.3	11	45.8
>1 - 6 years	2	22.2	1	11.1	2	66.7	2	28.6	8	30.8	5	20.8
>6 - <12 years	0	00	0	00	0	00	0	00	5	19.2	4	16.7
≥ 12 years	0	00	0	00	0	00	0	00	2	7.7	4	16.7
Birthplace according to the health macro-regions of Rio Grande do Sul[1]												
North	0	00	1	11.1	0	00	0	00	0	00	0	00
South	0	00	0	00	0	00	0	00	2	7.8	0	00
Center-West	6	75	5	55.6	2	66.7	4	57.1	20	76.9	21	87.5
Missioneira	2	25	2	22.2	0	00	2	28.6	3	11.5	2	8.3
Metropolitan	0	00	0	00	0	00	0	00	0	00	1	4.2
Vales	0	00	1	11.1	1	33.3	1	14.3	1	3.8	0	00
Origin according to health macro-regions of Rio Grande do Sul[1]												
North	0	00	1	11.1	0	00	1	14.3	0	00	0	00
South	0	00	0	00	0	00	0	00	1	3.8	0	00
Center-West	6	75	5	55.6	2	66.7	5	71.4	21	80.8	21	87.5
Missioneira	2	25	2	22.2	0	00	0	00	3	11.6	2	8.3
Metropolitan	0	00	0	00	0	00	0	00	0	00	1	4.2
Vales	0	00	1	11.1	1	33.3	1	14.3	1	3.8	0	00
Coming from Santa Maria												
Yes	5	55.6	2	22.2	1	33.3	2	28.6	9	34.5	9	37.6
No	4	44.4	7	77.8	2	66.7	5	71.4	17	65.5	15	62.4

Note. [1]The year 1995 has an *N* of 8 in the variables of birthplace and origin according to the health macro-region of Rio Grande do Sul because one of the medical records indicated the birthplace and origin in the State of Santa Catarina.

Most participants were male, except in 2005 and 2017, and white skin colored participants predominated in all the studied years. The predominant age range in most years was ≤ 1 year, except in 2005 when the age range >1-6 years was dominant. Regarding the birthplace and origin according to the health macro-regions of Rio Grande do Sul, the central-western region predominated.

Table 2 shows the participants' clinical and hospital discharge variables during the analyzed period.

Table 2

Clinical and hospital discharge profile of technology-dependent children and adolescents admitted to the PICU in 1995, 1997, 2005, 2007, 2015 and 2017

Clinical and Hospital Discharge Variables	Frequencies											
	1995		1997		2005		2007		2015		2017	
	N	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)
Pediatric E.R.	3	33,3	2	22,2	2	66,7	4	57,1	9	34,7	7	29,1
Admission Unit	1	11,2	2	22,2	0	00	0	00	1	3,8	4	16,7
Neonatal ICU	0	00	0	00	0	00	0	00	3	7,7	4	16,7
Transferred from another hospital	3	33,3	3	33,4	1	33,3	3	42,9	5	19,2	6	25,0
Home	0	00	0	00	0	00	0	00	0	00	0	00
Surgical Block	2	22,2	2	22,2	0	00	0	00	8	30,8	3	12,5
CT-Criac	0	00	0	00	0	00	0	00	1	3,8	0	00
Need for Cardiopulmonary Resuscitation												
Yes	0	00	3	33,3	0	00	2	28,6	0	0	0	00
No	9	100	6	66,7	3	100	5	71,4	26	100	24	100
Number of Readmissions before Hospital Discharge												
0	8	88,9	8	88,9	3	100	6	85,7	24	92,3	19	79,2
1	0	00	0	00	0	00	00	00	2	7,7	2	8,3
2	1	11,1	0	00	0	00	1	14,3	0	00	1	4,2
3	0	00	1	11,1	0	00	0	00	0	00	2	8,3
Use of Mechanical Ventilation												
Yes	7	77,8	6	66,7	0	00	6	85,7	11	42,3	15	62,5
No	2	22,2	3	33,3	3	100	1	14,3	15	57,7	9	37,5
Long-term Use of Medication												
Yes	4	44,4	4	44,4	2	66,7	3	42,9	13	50	18	75
No	5	55,6	5	55,6	1	22,3	4	57,1	13	50	6	25
Referred to the Outpatient Clinic												
Yes	5	55,6	7	77,8	3	100	5	71,4	11	21	22	91,7
No	4	44,4	2	22,2	0	00	2	28,6	15	5	2	8,3

Note. E.R. – Emergency Room; CT-Criac - Care Center for Children and Adolescents with Cancer.

The technology-dependent children and adolescents admitted to the PICU came mainly referred from the pediatric emergency room, and the majority of the participants did not need new admissions in the PICU before hospital discharge. Most participants needed mechanical ventilation in 1995, 1997, 2007, and 2017. Long-term medication use after hospital discharge showed differences in the examined periods, and in 1995, 1997, and 2007

most children and adolescents did not need it, while in 2005 and 2017, most of them did. The drug category standing out in this study was the anticonvulsants, and it was also observed that most participants were referred to outpatient care.

Table 3 shows all diagnoses organized according to the year.

Table 3

Diagnoses according to the ICD-10 of technology-dependent children and adolescents admitted to the PICU in 1995, 1997, 2005, 2007, 2015, and 2017.

Diagnoses	1995	1997	2005	2007	2015	2017
	N (%)	*N* (%)	*N* (%)	*N* (%)	*N* (%)	*N* (%)
Diseases of the respiratory system	7 (35)	4 (28.6)	3 (60)	5 (38.5)	7 (17.5)	15 (38.5)
Diseases of the nervous system	5 (25)	3 (21.4)	1 (20)	00	00	00
Diseases of the circulatory system	00	2 (14.3)	00	00	00	00
Certain conditions originating in the perinatal period	00	00	1 (20)	00	00	00
Congenital malformations, deformations, and chromosomal abnormalities	4 (20)	00	00	3 (23.1)	8 (20)	8 (20.5)
Certain infectious or parasitic diseases	00	00	00	2 (15.4)	00	7 (17.9)
Injury. poisoning or certain other consequences of external causes	00	00	00	00	6 (15)	00
Total	16	9	5	10	21	30

The respiratory system diseases headed the diagnoses in all studied years, except in 2015, when congenital malformations, deformations, and chromosomal abnormalities were predominant.

In terms of medical histories, in 1995, there was the same percentage (22.2%; *N* = 2) of congenital malformations, deformations, and chromosomal abnormalities, and certain conditions originating in the perinatal period. In 1997, the same frequency was observed in the diseases of the nervous system and certain conditions originating in the perinatal period (33.3%; *N* = 2). In 2005, no child/adolescent had a medical history before that current hospitalization. In 2007, 2015, and 2017, congenital malformations, deformations, and chromosomal abnormalities were the diagnoses with the highest percentage, accounting for 55.6% (*N* = 5), 61.7% (*N* = 16), and 41.9% (*N* = 18), respectively.

Table 4 describes all medical devices/technologies used by children/adolescents at the time of hospital discharge in the years of the study.

Table 4

Medical devices/technologies used by children/adolescents at the time of hospital discharge in 1995, 1997, 2005, 2007, 2015, and 2017

Medical devices/technologies used by children/adolescents at the time of hospital discharge	Frequencies											
	1995		1997		2005		2007		2015		2017	
	N	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)	*N*	(%)
Enteral/ gastric tube	6	66.7	2	22.2	1	33.3	4	57.1	7	22.6	4	12.1
Gastrostomy tube	3	33.3	1	11.1	2	66.7	2	28.6	9	29.0	12	36.3
Colostomy tube	00	00	2	22.2	00	00	00	00	1	3.2	1	3.0
Jejunostomy tube	00	00	1	11.1	00	00	00	00	00	00	00	00
VPS	00	00	2	22.2	00	00	1	14.3	9	29.0	7	21.2
Home Oxygen Therapy /MV	00	00	1	11.1	00	00	00	00	2	6.5	2	6.1
Tracheostomy	00	00	00	00	00	00	00	00	3	9.3	2	6.1
Wheelchair	00	00	00	00	00	00	00	00	00	00	2	6.1
Ileostomy pouch	00	00	00	00	00	00	00	00	00	00	2	6.1
Urinary catheter (intermittent or indwelling)	00	00	00	00	00	00	00	00	00	00	1	3.0

Note. VPS = ventriculoperitoneal shunt; MV = Mechanical ventilation.

The most used medical devices/technologies by children/adolescents during hospital discharge the most prevalent were enteral/gastric tubes, ventriculo peritoneal shunt (VPS), colostomy tubes, and gastrostomy tubes..

Discussion

When the hospitalizations of children and adolescents in PICUs are analyzed considering the biological sex (Benetti et al., 2020; Mendonça et al., 2019), the evidence is consistent. This study observes a predominance of the male sex among technology-dependent children and adolescents. This result aligns with Mendonça et al.'s study (2019) that analyzed the admissions at six PICUs in the State of Pernambuco and found that most corresponded to male patients. Thus, some authors consider the sexes have different adaptation abilities since the intrauterine period and that, after birth, the female sex presents better biological conditions and is less susceptible to developing health problems (Moreira et al., 2017; Da Silva & Fensterseifer, 2015).

A large part of the PICU admissions studied correspond to children between 0 and 1 year of age. This may allow inferring that the immaturity of the defense mechanisms is a predisposing factor to the need for specific healthcare. Benetti et al.'s study (2020) conducted in a university hospital also found a 41.6% predominance of children aged between 0 and 1 year of age in PICU admissions.

The prevalence of white skin colored patients in all the studied years corresponds to the reality of the Brazilian territory, considering that approximately 43.9% of children and adolescents considered themselves white in the last census conducted in 2010. According to the IBGE – *Instituto Brasileiro de Geografia e Estatistica* (Brazilian Institute of Geography and Statistics, 2010), the state of Rio Grande do Sul is composed of 80.21% of white skin colored children and adolescents.

Patients admitted to the PICU are mostly referred from the pediatric emergency room of the same health institution. This is because the hospital where this study was conducted is not considered an open-door service as it only receives patients referred by other health services or who are in emergency situations and are brought by ambulance.

The need for mechanical ventilation is observed in technology-dependent children and adolescents hospitalized in the years 1997, 2015, and 2017. A study developed to analyze the indicators of a PICU in the Brazilian city of Fortaleza based on the clinical diagnoses of the inpatients also pointed out a 75.3% rate of use of mechanical ventilation. The same study also examined the rate of mechanical ventilation duration for this population, considering that, depending on the clinical condition caused by the health problem, the duration of ventilatory support can be prolonged to maintain the body's vital activities (Oliveira et al., 2017).

Technology-dependent children and adolescents usually take several medications to maintain and stabilize their health. This study observes a predominance of the long-term use of anticonvulsants after hospital discharge. Okido et al.'s study (2016) aimed to understand the experience of mothers of technology-dependent children in medication management. They also observed that the drug category most commonly used daily was anticonvulsants, followed by antibiotics, antihypertensive medication, anti-reflux medication, supplements and vitamins, corticosteroids, and muscle relaxants.

The primary diagnoses identified by this study are diseases of the respiratory system, followed by congenital malformations, deformities, and chromosomal anomalies. The

scientific evidence points out that the diagnoses of children and adolescents at the PICU are usually associated with respiratory problems and related to the development of pneumonia (Benetti et al., 2020; Andrade et al., 2016). In general, technology-dependent children and adolescents have previous diseases (i.e., medical history), among which the cases of certain conditions originating in the perinatal period, congenital malformations, deformities, and chromosomal anomalies, and diseases of the nervous system stand out. The existence of a past medical history adds to the complexity of the clinical conditions of technology-dependent children and adolescents, often prolonging hospitalization. Thus, to provide quality care effectively, some factors involved in the admission process of these patients to the PICU must be evaluated.

At the time of hospital discharge, the medical devices/technologies most used by children and adolescents the enteral/gastric tube, the gastrostomy tube, the colostomy tube, and VPS. The study conducted by Lima et al. (2018) in a PICU of a teaching hospital in the state of Paraná observed that technology-dependent children usually have more than one diagnosis and that the use of tracheostomy tubes, gastrostomy tubes, mechanical ventilators, enteral tubes, and urinary catheters stand out among the medical devices/ technologies used.

This study is limited by being conducted in a hospital in only one Brazilian region. Thus, expanding the research to other institutions in different regions of the country is recommended. The new knowledge emerging from this study is the understanding that this group of patients has grown in recent years at the studied PICU. Moreover, this study also includes data about adolescents, a group generally neglected in studies involving medical device/technology dependence. The results of this study align with that of others, as they point out that the leading causes of admission to the PICU are respiratory diseases, the medical histories primarily responsible for chronicity are certain conditions originating in the perinatal period, and anticonvulsant drugs are the most used by this population.

Conclusion

The demographic profile of technology-dependent children and adolescents admitted to a PICU of a public hospital in the central region of Rio Grande do Sul indicates a predominance of white male children aged up to 1 year. These children are from the hospital's central-western region of reference and were referred from the pediatric emergency room of the hospital where this study was developed.

Regarding clinical conditions, most children/adolescents have a medical history of conditions originating in the perinatal period, congenital malformations, deformations, and chromosomal abnormalities, and diseases of the nervous system. Diseases of the respiratory system and congenital malformations, deformations, and chromosomal abnormalities predominate as diagnoses for the present hospitalization. This study also demonstrates the long-term use of medication, with anticonvulsant drugs standing out, and the need for mechanical ventilation in this population segment. At the moment of hospital discharge, enteral/gastric tubes, gastrostomy tubes, colostomy tubes, and VPS are the most used medical devices/technologies. This study provides greater visibility to technology-dependent children/adolescents, considering that their diagnoses require more intensive, complex, and continuous care. Thus, this group is a challenge for professionals and health services, as apart from the current cause of hospitalization, past medical histories can often interfere with the prognosis. Thus, healthcare teams must plan care actions considering the child or adolescent and their caregivers to ensure the delivery of comprehensive care. The results of this study point to the need for further research on this healthcare theme so that care delivery to this population aligns with their clinical and social needs.

Author Contributions

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